

Psychosexual support for gynecological cancer survivors: professionals' current practices and need for assistance

Willemijn M. Vermeer · Rinske M. Bakker ·
Anne M. Stiggelbout · Carien L. Creutzberg ·
Gemma G. Kenter · Moniek M. ter Kuile

Received: 21 May 2014 / Accepted: 2 September 2014 / Published online: 14 September 2014
© Springer-Verlag Berlin Heidelberg 2014

Abstract

Purpose About half of the gynecological cancer (GC) survivors suffer from sexual dysfunctions and report a need for professional psychosexual support. The current study assessed (1) health care professionals' (HCP) current psychosexual support practices, (2) barriers to providing psychosexual support, and (3) HCP needs for training and assistance.

Methods Semistructured interviews were conducted with gynecological oncologists ($n=10$), radiation oncologists ($n=10$), and oncology nurses involved in the treatment of GC ($n=10$).
Results The majority of the professionals reported discussing sexuality at least once with each patient. An important reason for addressing sexual functioning was to reassure patients that it is normal to experience sexual concerns and give them an opportunity to discuss sexual issues. About half of the professionals provided specific suggestions. Patients were rarely referred to a sexologist. Barriers encountered by professionals in the provision of psychosexual support were embarrassment and lack of time. HCP suggestions for the facilitation of psychosexual support provision were skills training, an increased availability of patient information, and the standard

integration of psychosexual support in total gynecological cancer care.

Conclusion The majority of the professionals reported discussing sexuality at least once with every patient, but discussions of sexual functioning were often limited by time and attention. The development of comprehensive patient information about sexuality after GC is recommended as well as a more standard integration of psychosexual support in GC care and specific training.

Keywords Female sexual dysfunction · Gynecological cancer · Psychosexual support · Qualitative analysis

Introduction

In recent years, quality of life issues of gynecological cancer (GC) survivors have received increasing attention. Sexual health is an important issue that is often negatively affected by cancer treatments. Sexual dysfunctions can be distressing [1–4] and have been reported in 23 to 63 % of patients treated for GC [1, 5–11]. According to Dutch national guidelines [12], each cervical cancer (CC) patient (and her partner) should receive counseling about possible treatment consequences for sexual functioning.

Previous studies have shown that many (gynecological) cancer survivors report a need for information and care for their sexual concerns [13–16]. Studies have shown that survivors have a need for information and practical advice about coping with sexual complaints. Additionally, many survivors with a need for psychosexual support do not seek or receive the information or professional help that they desire [15–20]. Feelings of embarrassment or expectations that the doctor lacked time to discuss these issues appeared to be barriers for GC survivors to seek professional help [16, 21].

W. M. Vermeer (✉) · R. M. Bakker · M. M. ter Kuile
Department of Gynecology, Leiden University Medical Center, P.O.
BOX 9600, 2300 RC Leiden, The Netherlands
e-mail: w.m.vermeer@lumc.nl

A. M. Stiggelbout
Department of Medical Decision Making, Leiden University Medical
Center, Leiden, The Netherlands

C. L. Creutzberg
Department of Clinical Oncology, Leiden University Medical Center,
Leiden, The Netherlands

G. G. Kenter
Centre for Gynecological Cancer Amsterdam, Amsterdam, The
Netherlands

While women only occasionally initiate discussions with their doctor about sexuality, in many cases, health care professionals (HCPs) fail to raise the topic of sexuality. Studies have shown that nearly all professionals involved in caring for women diagnosed with GC thought that sexual issues should be discussed with their patients, but only 21 to 49 % actually did so [20, 22, 23]. If they occur at all, conversations about sexuality are often limited to a general question with a medical-technical focus on sexual functioning, such as whether women are able to have sexual intercourse [22, 24–26]. The most frequently reported explanation for refraining from discussing sexual issues is the view that it is not one's responsibility or even that it is felt to be inappropriate to discuss sexuality with a patient [22, 26, 27]. Other reasons were embarrassment, insufficient possibilities for referral, and a lack of privacy, time, or skills [24, 26].

The aforementioned studies mostly focused on attitudes and current behaviors with respect to providing psychosexual support. Less is known about barriers that professionals experience and how professionals can be facilitated with the provision of information and care for sexual concerns. The aim of the current study was to assess (1) HCP current psychosexual support practices, (2) barriers to provide psychosexual support, and (3) HCP needs for training and assistance.

Methods

Participants and recruitment procedures

In this qualitative study, semistructured interviews were conducted with HCPs. We aimed to include one gynecological oncologist (GynO), one radiation oncologist (RadO), and one oncology nurse specialized in gynecology (OncN) in the study from each of the nine Dutch centers for gynecological oncology. One of the centers had two sites, which were both represented by participants in this study. This means that a purposive sample of $n=30$ professionals was included, to evenly represent all sites involved in the care for women with gynecological malignancies in the Netherlands. A mailing was sent to 36 GynOs and RadOs representing all nine Dutch centers. The recipients of the mailing were asked to identify one GynO and one RadO to represent their center. A snowballing strategy was used to recruit OncN via the GynO and RadO. Recipients who did not reply within 1 week were telephoned to ask if they were willing to make an appointment for an interview. The local ethics committee deemed the study exempt from formal clearance. The study was deemed exempt from review by the institutional review board.

Data collection and interview topics

Face-to-face interviews were conducted with 22 participants; for practical reasons, the other eight participants were

interviewed by telephone. The interviews took approximately 25 min (ranging from 15 to 39 min). All interviews were audio taped and transcribed verbatim. The topics discussed were the following: the patient population and commonly reported sexual problems, current practices regarding information and care provision, barriers to providing psychosexual support, and needs for training and assistance. See Table 1 for more details about the interview topics. Additionally, participants were asked to complete a short survey with questions about their age, work experience, and how often they provided psychosexual support (never, sometimes, regularly, often).

Data analyses

The data were coded and analyzed with NVivo version 10 [28] using the framework approach. The framework approach is a combination of a deductive and an inductive coding specifically developed for policy-relevant qualitative research [29]. After familiarization with the data, WV made a first version of a coding scheme that was based on the interview guide. Subsequently, RB and WV independently coded a random sample of three interviews and compared their coding. New codes that emerged from the data were discussed and, if deemed of added value, added to the codebook. Any discrepancies in coding were resolved through negotiated consensus. WV and RB repeated this procedure 5 times until 15 interviews were coded. The remaining 15 interviews were divided between RB and WV. To support reliability, RB and WV cross-checked and complemented each other's coding after every third interview until all 30 interviews were coded [30].

Results

The average age of the participants was 49 years ($SD=9$), and the majority ($n=23$, 77 %) were female. Almost two thirds of the participants ($n=18$, 64 %) had more than 10 years of experience in gynecological oncology, 25 % ($n=7$) had 5 to 10 years of experience, and 3 participants (11 %) had less than 5 years of experience (missing $n=2$). Furthermore, 45 % ($n=14$) of the participants reported regularly providing psychosexual support to patients, 8 participants (29 %) reported providing this often, and 6 participants (21 %) sometimes (missing $n=2$).

Patient population and perceived sexual dysfunctions

Table 2 provides an overview of quotes supporting and illustrating the results. The professionals' patient population consisted of women diagnosed with (in order of prevalence) CC, vulvar cancer, endometrial cancer, ovarian cancer, vaginal cancer, and trophoblastic tumors. Various sexual dysfunctions were mentioned that could occur as a consequence of the

Table 1 Interview topics

Topics	Questions
Patient population and sexual problems	-Description of patient population. -Description of sexual problems of patient population.
Current practices regarding information and care provision	-Information and care that is provided. -Availability (and content) of protocol for information and care provision. -Modes of information and care provision. -Tailoring information and care. -Partner involvement. -Organization of information and care provision.
Barriers	-Barriers to providing information and care.
Need for training and assistance	-Suggestions to be better facilitated in the provision of psychosexual support.

cancer treatment, such as reduced sexual arousal or libido, (anxiety for) pain during sexual intercourse, and tiredness. Some professionals mentioned that, specifically in GC versus other malignancies, the body parts that gave sexual pleasure were associated with the disease and treatment (quote 1). Participants generally had the impression that the number of sexual dysfunctions and distress patients experienced depended on different factors such as patients' age, coping issues, relational problems, in addition to the issues that were related to the gynecological malignancy. Half of the professionals thought that the impact of sexual dysfunctions on distress was greater for younger women who were more often sexually active before and after treatment. Furthermore, some professionals mentioned that treatments could have different effects on sexual functioning. For example, radiotherapy was specifically associated with vaginal adhesions, stenosis, atrophy, dryness, and a damaged epithelium. Professionals mentioned fatigue, feeling depressed, decreased mucous membrane formation as side effects of chemotherapy that could affect sexual functioning. Surgery led to anatomical changes of the vagina according to the professionals. CC survivors were especially identified as being at higher risk of suffering from sexual distress, since this patient group is relatively young and the treatment has significant effects on sexual function.

Current practices of providing psychosexual support

Timing of information and care provision

Nearly half of the professionals explicitly reported considering the provision of psychosexual support as part of standard

cancer care (quote 2). Prior to the treatment, the information that professionals mostly provided consisted of possible treatment consequences on sexual functioning (e.g., lubrication, narrowing, or shortening of the vagina). In some cases, professionals told their patients that, if needed in the future, support for sexual concerns was available. A small minority of the professionals reported not providing any information before treatment. An important reason for professionals to initiate conversations about sexuality was to address the topic and thereby encourage patients to raise any related issues (quote 3). Almost all professionals reported addressing sexuality during follow-up, mostly by asking their patients about their sexual functioning.

Methods of information and care delivery

Participants were also asked which mode of delivery they used to provide the information about GC and sexuality. The large majority indicated providing only verbal information. Three professionals stated that a brochure was available at their hospital, and three reported referring their patients to a Dutch Cancer Society booklet on cancer and sexuality. With respect to the Internet, five participants reported referring their patients to Web sites of patient support groups.

Professionals generally stated that they initiated discussions about sexual functioning, rather than the patient. About two thirds of the professionals (especially GynO) reported talking about sexuality with each woman diagnosed with a gynecological malignancy (quote 4). When asking their patients about sexuality, five professionals (of whom four OncNs) mentioned using a general screening instrument such as a problem list sometimes used as a supplement to the Distress Thermometer [31] and comprising one item about problems with sexuality. As a result, this topic normally received attention, according to these professionals.

Content of the information

About half of the professionals gave women information about lubricant use and advised on or (if authorized) prescribed hormonal therapy. There were also a few professionals who added that the prescription of hormonal therapy depended on whether the tumor was hormone-sensitive. Lastly, five professionals advised women to explore their body and have noncoital sex and/or gave advice on sexual positions. A large group of professionals mentioned the possibility of referring patients to a sexologist, although most of them said that this only actually happened a few times per year.

Additionally, almost every professional reported tailoring the content and quantity of the information and care provided

Table 2 Topics and quotes

Topic	Quote no.	Quote
Patient population and sexual problems		
Sensitive nature of the cancer site	1	RadO, female, >10 years of experience: Whichever way you look at it, I think that rehabilitating from cancer is simply very difficult. And compared to all other types of cancer, it is even more complicated in the case of gynecological cancer and sexuality. Because that area of the body is associated with so much anxiety and insecurity, while at the same time it is also a source of uncomplicated relaxation and pleasure.
Current practices regarding information and care provision		
Task perception	2	RadO, female, >10 years of experience: Well, if the patient does not initiate a conversation about sexuality, I consider it my duty to start talking about it. And in most of the cases, you have to start talking about it yourself. Sometimes, a patient raises the topic, but if not, it is absolutely our task to address sexuality. You irradiate somebody for seven, eight weeks, so you interact intensively. Yes, I do think that is part of our treatment and care provision. We cause it [referring to vaginal changes].
Information provision can function as permission giving	3	GynO, male, 5–10 years of experience: But I am really convinced that [referring to addressing sexuality] we have to do that. And even if you only briefly raise the topic, then patients have heard about it. This makes it easier to come back to the topic after the operation, and makes it clear to the patient too that she can bring up the matter in case of [sexual] complaints.
Adapting the amount of psychosexual support to individual patient characteristics	4	GynO, male, 5–10 years of experience: The only reason for not asking about sexual functioning is that I've heard repeatedly that it is not an issue, because that woman has indicated that it is not an issue. It can be that she is a widow and eighty. It can be that her husband is impotent. It can be that she has never enjoyed it. Or that it is only an excuse for not having to think about sexuality anymore. Then I stop raising the topic. But first that has to be confirmed clearly.
Rationale for vaginal dilation	5	RadO, female, <5 years of experience: In the case of older vulvar carcinoma patients I don't ask. Because they are often.. The anatomy changes so much, it all gets dry and hard, and actually most cannot be sexually active anymore.. Unless, women are younger, then I do discuss it. In the case of a younger woman, I don't have any difficulties asking whether they are sexually active.
Barriers		
Sexuality is a taboo topic	6	GynO, male, 5–10 years of experience: Interviewer—To what extent is vaginal dilation necessary for check-ups during follow-up? Participant—Well, it is difficult to see anyway. It is more important to feel, and we can do that rectally as well. If you really don't know, then you can make an ultrasound. So, I don't think that is a valid reason. Especially not, later in the follow-up process.
	7	OnaN, female, >10 years of experience: I think that the nature of the people here is that they do not feel free to discuss things. That's what you notice. Also because, in general, it is an older patient population, sexuality and sexual problems are not topics that people easily discuss. You notice that younger people

Table 2 (continued)

Topic	Quote no.	Quote
No focus on sexuality	8	<p>are much more at ease doing this. And for myself, I also really had to learn that, because I am also from a generation that barely talked about that.</p> <p>RadO, male, >10 years of experience: It remains a difficult topic to start talking about. Especially if you don't know a patient very well and you don't know about their attitudes. Follow-up check-ups are primarily directed at., of course the focus is on whether the tumor is gone: 'How is the patient doing?'. Often people have bothersome side effects on the bladder or bowel, and then it [sexuality] moves more to the background.</p> <p>RadO, male, >10 years of experience: But, in these times, are you going to hire people for that [referring to psychosocial care in general]? That costs a lot of money. That sort of patients cost a lot of time. You are not going to talk about such issues for five minutes. That easily takes a quarter or half an hour.</p>
Lack of time and resources	9	<p>RadO, male, >10 years of experience: The topic [referring to sexuality] is difficult to discuss. So, I would like to know or have some help with how to bring it to someone's attention if I think that is needed while the patient remains aloof. You simply have people who want to keep that to themselves, while I think: then you will be facing some problems in the future.</p>
Need for training and assistance	10	<p>RadO, male, >10 years of experience: I think that it would be good if, in addition to the information that can be provided in the consulting room, something is available on the Internet. A video or something that shows people what the problems are. Especially because it can help people understand that they are not the only ones having these problems.</p>
Need for patient information	11	<p>RadO, male, >10 years of experience: If I could change one thing, then I think that taking a sexual history should be an integral part of the general history. That you are accessible for patients with sexual concerns and that they receive good interventions and aids.</p>
Need for formal integration of sexuality in care	12	<p>RadO, female, >10 years of experience: I think that maybe we make too little use of sexologists. That we leave that too much aside and that we are more focused on oncological rather than on psychological aspects. here is room for improvement here.</p>
Involvement of other professionals	13	<p>RadO, female, >10 years of experience: I think that maybe we make too little use of sexologists. That we leave that too much aside and that we are more focused on oncological rather than on psychological aspects. here is room for improvement here.</p>

to patient characteristics (e.g., age, type of cancer and treatment, sexual activity, expressed need for information or support). In the case of older (>80 years) and single patients, a minority of the professionals reported either not or scarcely addressing sexuality at all (quote 5).

A large majority of the professionals reported advising patients treated with RT to use plastic dilator sets or have intercourse to prevent adhesions and to keep the vagina accessible. Some professionals added that this was important to enable successful sexual intercourse and/or physical examinations. There were also a few participants that stated, however, that dilator use was too onerous to recommend solely to facilitate physical examination (quote 6).

Furthermore, the majority of the medical centers made agreements on the provision of information and support for the use of vaginal dilators. Commercially available plastic dilator sets were most frequently recommended. If patients preferred, however, vibrators and tampons covered with Vaseline were suitable as well according to the HCP.

Most participants said that in their centers, the HCPs (particularly the RadOs) were responsible for offering information and care about vaginal dilator use. A few said that this was part of the OncN's responsibilities, or that of the center's sexologist or pelvic floor physiotherapist.

Partner involvement

More than half of the professionals were in favor of involving the partner in the information and care provision relating to sexual functioning (these were predominantly GynOs and OncNs), whereas some others said that it is up to the patient to what extent her partner is involved. Furthermore, professionals stated that some patients were more inhibited to discuss sexuality in the presence of their partner. Three professionals considered it their responsibility to focus on the patient and not on the partner when discussing sexuality.

Organization of information and care provision

The organization of psychosexual support provision varied between the participating centers. Half of the professionals reported having a protocol or mutual agreements within their center about who should provide information and care for sexual functioning after treatment of GC. Surprisingly, professionals within the participating centers sometimes had differing opinions about whether or not there was a protocol or mutual agreements. The other half of the professionals said that no agreements or protocols were available and that the quantity and quality of psychosexual support depended on the individual professional.

A large majority of the professionals thought that the provision of psychosexual support was a shared responsibility

of the GynO, RadO, and OncN. Some of them, however, thought that it was mostly the HCP's responsibility to inform the patient and that the OncN was expected to check and complement the information that was provided. Alternatively, other professionals were in favor of a strong engagement of the OncNs in the information and care provision around sexuality. Advantages that were mentioned were that OncNs were more accessible, had more time, and were less costly than doctors (mentioned most frequently by OncNs). At the same time, many OncNs said that they had contact with their patients once or twice at most after the treatment. This was an important reason for not being able to pay much attention to care for sexual concerns.

Barriers

The majority of the professionals reported initiating conversations about sexuality, but at the same time, many described sexuality as a taboo topic. According to many, patients often had difficulties talking about sexuality (quote 7). A few professionals also said that they felt uncomfortable themselves, currently or in the past, talking sexuality (quote 7). About half of all professionals currently had no problem talking about sexuality, which was often attributed to experience. Another factor that could make it difficult to address sexual functioning, according to about half of the professionals, was that before and shortly after treatment patients (and professionals too) were focused on their disease, treatment, and survival rather than on sexuality (quote 8). Therefore, some professionals were afraid of burdening their patients by addressing sexuality too much. One third of the professionals mentioned practical barriers such as lack of time (quote 9).

Need for training and assistance

More than one third of the professionals stated to appreciate receiving more education and/or training in discussing a sensitive topic such as sexuality with their patients (quote 10). Professionals would also like to learn more about (coping with) sexual dysfunctions after cancer to better inform their patients. For the purpose of informing patients, one third of the professionals also wished to have more information accessible to their patients. According to these professionals, information should address possible treatment consequences, state that it is common to experience sexual concerns, give practical advice (for instance about different lubricants) and strategies for dealing with sexual dysfunctions (quote 11). One professional additionally stressed that it was important to tailor the information to the patient's individual situation, for instance with respect to the type of cancer and treatment. Furthermore, one third of the professionals were either in favor or already used a protocol or formal agreements with respect to the provision of psychosexual support (quote 12). One professional was

somewhat hesitant and stated that too many protocols are being developed in health care. A small group of professionals specifically mentioned being in favor of (empirically based) guidelines or instructions for vaginal dilation and a more patient-friendly design of dilators. Lastly, a few professionals expressed the need to have more possibilities for involving other professionals (e.g., sexologists, physiotherapists, social workers) in the psychosexual support provision (quote 13).

Discussion

The interviews revealed that the majority of the professionals reported addressing sexuality at least once with every GC patient. This was done by informing women before treatment about possible treatment consequences on sexuality or by asking them about their sexual functioning during follow-up. An important reason for that was to reassure patients that sexuality was an acceptable topic to discuss. These results are in accordance with the PLISSIT model. The PLISSIT model differentiates four levels of psychosexual interventions and can be used to include sexuality into the clinical oncologic practice [32, 33]. The interviews suggest that most professionals applied the first two levels of the PLISSIT model in their current practice by giving patient permission to talk about sexuality (level 1) and supplying them with limited information (level 2). Depending on patient characteristics, such as age, partner status, or severity of sexual concerns, some professionals reporting paying more attention to sexuality. About half of the professionals advised their patients about lubricant use, and a few advised women about noncoital sex or sexual positions. This kind of specific suggestions falls within level 3 of the PLISSIT model. In line with other research [20], professionals reported referring their patients very rarely to a sexologist for intensive therapy (level 4).

The second research question was directed at barriers that professionals encountered in providing psychosexual support. A frequently mentioned barrier was patients' and professionals' embarrassment about discussing sexuality. Furthermore, the participants reported that during follow-up they, as well as their patients, were often focused on medical aspects such as disease recurrence, which could get in the way of discussing sexuality. This is in line with findings from a study by White and colleagues who described this focus as the biomedical gaze [26]. Lastly, in line with results from a review on sexual health communication during cancer care [34–36], practical barriers such as lack of time were reported.

With respect to the third research question, there was a need for more knowledge about sexuality after cancer and training to improve professionals' skills when raising a sensitive topic like sexuality. Second, professionals would like to have more resources available to which they could refer their patients for

further information. Some professionals indicated referring their patients to the Web site of the patient organization for GC or giving patients a Dutch Cancer Society booklet about cancer and sexuality. It should, however, be noted that this Web site contains very little information about sexuality after GC and that the booklet is not directed at sexual problems specific to GC. Third, some professionals advocated an integration of psychosexual support in the cancer care protocols. This finding is in line with recommendations to incorporate the assessment of sexual difficulties right from the initial evaluation of patients with cancer throughout treatment and recovery [37, 38]. One strategy that integrates psychosexual support in cancer care was applied by a small minority of the professionals, by including sexual concerns in routine problem lists that patients complete before seeing their health care provider during follow-up [33]. A fourth recommendation is to explore possibilities for more involvement of OncNs in psychosexual support. One organizational barrier for OncN involvement was that in many cases, OncNs did not see GC survivors during follow-up care. To enhance OncN involvement in psychosexual support, the organization of follow-up care and the position of the OncNs therein should be altered. Giving OncNs more responsibilities in the psychosexual support provision could additionally reduce health care costs. Lastly, professionals would like to have clearer guidelines about dilator use in order to advise their patients.

The majority of the professionals indicated addressing sexuality at least once with every patient. This sheds a more positive light on HPC's attention for sexual functioning of GC survivors compared to other studies in this field [20, 22–24, 26]. Studies into the provision of psychosexual support have primarily been conducted in Anglo-Saxon countries. Attitudes toward sexuality are culturally determined [34] and likely translated into the psychosexual support that is being offered. Therefore, one explanation might be that this study was conducted in the Netherlands where attitudes toward sexuality are generally progressive [39]. Another explanation might be that the HCPs who participated in this study were inclined to provide socially desirable responses and overstate the importance that they attach to psychosexual support.

Even though there are some methodological explanations for the relatively strong emphasis placed on sexual functioning of GC survivors among the professionals who participated in this study, it is a promising result. This study, however, also demonstrated that, apart from encouraging the discussion of sexuality and providing patients with limited information, levels 3 and especially 4 of the PLISSIT model were not regularly included in professionals' current practice. This finding is in line with a questionnaire and interview study among Dutch CC survivors revealing that sexuality was discussed with the majority of the patients [16, 40]. According to the patients, however, the conversations with professionals about sexuality were often short, general, and

with a medical focus on sexual functioning [40]. Other studies in this area have also demonstrated HCP tendency to limit conversations with their patients about sexuality to penetrative sexual intercourse [41–43], and we think that the quality of psychosexual support could be improved if attention for sexuality also encompasses issues such as maintaining intimacy and noncoital sexual activity [44, 45].

Conclusions

Many professionals reported addressing sexuality at least once with every patient. Although this is a hopeful finding, the attention to sexual function after GC was generally limited. In order to better support women's sexual rehabilitation after GC, professionals should put more emphasis on providing GC survivors with information about sexuality and specific suggestions about coping with sexual complaints, refer them to a sexologist if needed, and include themes around intimacy and noncoital sexual intercourse in the information and care provision. The development of more comprehensive patient information about sexuality after GC is recommended as well as more formal integration of psychosexual support in cancer care.

Acknowledgments This study was supported by the Dutch Cancer Society (grant no. UL 2010-4760).

Conflicts of interest The authors declare no financial disclosures or conflict of interests. The authors also have full control of the primary data and agree to allow the journal to review the data if requested.

References

- Bergmark K, Avall-Lundqvist E, Dickman PW, Henningsohn L, Steineck G (1999) Vaginal changes and sexuality in women with a history of cervical cancer. *N Engl J Med* 340:1383–9. doi:10.1056/NEJM199905063401802
- Bergmark K, Avall-Lundqvist E, Dickman PW, Henningsohn L, Steineck G (2002) Patient-rating of distressful symptoms after treatment for early cervical cancer. *Acta Obstet Gynecol Scand* 81:443–450
- Hazewinkel MH, Sprangers MA, Velden J, Burger MP, Roovers JP (2012) Severe pelvic floor symptoms after cervical cancer treatment are predominantly associated with mental and physical well-being and body image: a cross-sectional study. *Int J Gynecol Cancer* 22:154–60. doi:10.1097/IGC.0b013e3182332df8
- Juraskova I, Butow P, Bonner C, Robertson R, Sharpe L (2013) Sexual adjustment following early stage cervical and endometrial cancer: prospective controlled multi-centre study. *Psychooncology* 22:153–9. doi:10.1002/pon.2066
- Abbott-Anderson K, Kwekkeboom KL (2012) A systematic review of sexual concerns reported by gynecological cancer survivors. *Gynecol Oncol* 124:477–489. doi:10.1016/j.ygyno.2011.11.030
- Frumovitz M et al (2005) Quality of life and sexual functioning in cervical cancer survivors. *J Clin Oncol* 23:7428–36. doi:10.1200/JCO.2004.00.3996
- Grumann M, Robertson R, Hacker NF, Sommer G (2001) Sexual functioning in patients following radical hysterectomy for stage IB cancer of the cervix. *Int J Gynecol Cancer* 11:372–80
- Jensen PT et al (2004) Early-stage cervical carcinoma, radical hysterectomy, and sexual function. A longitudinal study *Cancer* 100:97–106. doi:10.1002/cncr.11877
- Lindau ST, Gavrilova N, Anderson D (2007) Sexual morbidity in very long term survivors of vaginal and cervical cancer: a comparison to national norms. *Gynecol Oncol* 106:413–418. doi:10.1016/j.ygyno.2007.05.017
- Pieterse QD et al (2013) Self-reported sexual, bowel and bladder function in cervical cancer patients following different treatment modalities: longitudinal prospective cohort study. *Int J Gynecol Cancer* 23:1717–25. doi:10.1097/IGC.0b013e3182a80a65
- Pieterse QD et al (2006) An observational longitudinal study to evaluate miction, defecation, and sexual function after radical hysterectomy with pelvic lymphadenectomy for early-stage cervical cancer. *Int J Gynecol Cancer* 16:1119–29. doi:10.1111/j.1525-1438.2006.00461.x
- Cervixcarcinoom LR Cervixcarcinoom (3.0), I.K.C. Nederland, Editor. 2012, Integraal Kankercentrum Nederland (IKNL): Utrecht.
- Hill EK et al (2011) Assessing gynecologic and breast cancer survivors' sexual health care needs. *Cancer* 117:2643–51. doi:10.1002/cncr.25832
- Rasmusson E, Thome B (2008) Women's wishes and need for knowledge concerning sexuality and relationships in connection with gynecological cancer disease. *Sex Disabil* 26:207–218. doi:10.1007/s11195-008-9097-5
- Rasmusson EM, Plantin L, Elmerstig E (2013) 'Did they think I would understand all that on my own?' A questionnaire study about sexuality with Swedish cancer patients. *Eur J Cancer Care (Engl)* 22:361–9. doi:10.1111/ecc.12039
- Vermeer WM, et al. (In press) Sexual issues among cervical cancer survivors: how can we help women seek help?
- Flynn KE et al (2012) Patient experiences with communication about sex during and after treatment for cancer. *Psychooncology* 21:594–601. doi:10.1002/pon.1947
- Gilbert E, Perz J, Ussher JM (2014) Talking about sex with health professionals: the experience of people with cancer and their partners. *Eur J Cancer Care (Engl)*. doi:10.1111/ecc.12216
- Scanlon M et al (2012) Patient satisfaction with physician discussions of treatment impact on fertility, menopause and sexual health among pre-menopausal women with cancer. *J Cancer Educ* 3:217–25. doi:10.7150/jca.4408
- White ID, Allan H, Faithfull S (2011) Assessment of treatment-induced female sexual morbidity in oncology: is this a part of routine medical follow-up after radical pelvic radiotherapy? *Br J Cancer* 105:903–10. doi:10.1038/bjc.2011.339
- McCallum M, Lefebvre M, Jolicoeur L, Maheu C, Lebel S (2012) Sexual health and gynecological cancer: conceptualizing patient needs and overcoming barriers to seeking and accessing services. *J Psychosom Obstet Gynaecol* 33:135–42. doi:10.3109/0167482x.2012.709291
- Stead ML, Brown JM, Fallowfield L, Selby P (2003) Lack of communication between healthcare professionals and women with ovarian cancer about sexual issues. *Br J Cancer* 88:666–671. doi:10.1038/sj.bjc.66007996600799
- Wiggins DL, Wood R, Granai CO, Dizon DS (2007) Sex, intimacy, and the gynecologic oncologists: survey results of the New England Association of Gynecologic Oncologists (NEAGO). *J Psychosom Oncol* 25:61–70. doi:10.1300/J077v25n04_04
- Hordern AJ, Street AF (2007) Constructions of sexuality and intimacy after cancer: patient and health professional perspectives. *Soc Sci Med* 64:1704–1718. doi:10.1016/j.socscimed.2006.12.012
- Stilos K, Doyle C, Daines P (2008) Addressing the sexual health needs of patients with gynecologic cancers. *Clin J Oncol Nurs* 12:457–63. doi:10.1188/08.CJON.457-463

26. White ID, Faithfull S, Allan H (2013) The re-construction of women's sexual lives after pelvic radiotherapy: a critique of social constructionist and biomedical perspectives on the study of female sexuality after cancer treatment. *Soc Sci Med* 76:188–96. doi:10.1016/j.socscimed.2012.10.025
27. Traa MJ, De Vries J, Roukema JA, Rutten HJ, Den Oudsten BL (2014) The sexual health care needs after colorectal cancer: the view of patients, partners, and health care professionals. *Support Care Cancer* 22:763–72. doi:10.1007/s00520-013-2032-z
28. NVivo. 1990–2013, QSR International: Melbourne, Australia.
29. Pope C, Ziebland S, Mays N (2000) Qualitative research in health care. *Analysing qualitative data*. *BMJ* 320:114–116
30. Mays N, Pope C (1995) Rigour and qualitative research. *BMJ* 311: 109–12
31. Distress Management Clinical Practice Guidelines in Oncology (2003) *Journal of the National Comprehensive Cancer Network* 1: 344.
32. Cleary V, McCarthy G, Hegarty J (2012) Development of an educational intervention focused on sexuality for women with gynecological cancer. *J Psychosoc Oncol* 30:535–55. doi:10.1080/07347332.2012.703767
33. Katz A (2005) The sounds of silence: sexuality information for cancer patients. *J Clin Oncol* 23:238–241. doi:10.1200/jco.2005.05.101
34. Dyer K, Das Nair R (2013) Why don't healthcare professionals talk about sex? A systematic review of recent qualitative studies conducted in the United Kingdom. *J Sex Med* 10:2658–2670. doi:10.1111/j.1743-6109.2012.02856.x
35. Hautamaki K, Miettinen M, Kellokumpu-Lehtinen PL, Aalto P, Lehto J (2007) Opening communication with cancer patients about sexuality-related issues. *Cancer Nurs* 30:399–404. doi:10.1097/01.NCC.0000290808.84076.97
36. Park ER, Norris RL, Bober SL (2009) Sexual health communication during cancer care: barriers and recommendations. *Cancer J* 15:74–7. doi:10.1097/PPO.0b013e31819587dc
37. McKee AL, Jr., Schover LR (2001) Sexuality rehabilitation. *Cancer* 92:1008–12. doi: 10.1002/1097-0142(20010815)92:4+<1008::AID-CNCR1413>3.0.CO;2-2 [pii].
38. Ofnan U (2004) "...And how are things sexually?" helping patients adjust to sexual changes before, during, and after cancer treatment. *Support Cancer Ther* 1:243–7. doi:10.3816/SCT.2004.n.017
39. Widmer ED, Treas J, Newcomb R (1998) Attitudes toward nonmarital sex in 24 countries. *J Sex Res* 35:349–358. doi:10.1080/00224499809551953
40. Vermeer WM, Bakker RM, Kenter GG, Stiggelbout AM, ter Kuile MM (Submitted for publication) Talking about a difficult topic: cervical cancer survivors' and partners' experiences with sexual dysfunction and psychosexual support.
41. Faithfull S, White I (2008) Delivering sensitive health care information: challenging the taboo of women's sexual health after pelvic radiotherapy. *Patient Educ Couns* 71:228–233. doi:10.1016/j.pec.2007.12.011
42. Hordern AJ, Street AF (2007) Communicating about patient sexuality and intimacy after cancer: mismatched expectations and unmet needs. *Med J Aust* 186:224–227
43. Ussher JM et al (2013) Talking about sex after cancer: a discourse analytic study of health care professional accounts of sexual communication with patients. *Psychol Health* 28:1370–90. doi:10.1080/08870446.2013.811242
44. Krychman ML, Pereira L, Carter J, Amsterdam A (2006) Sexual oncology: sexual health issues in women with cancer. *Oncology* 71: 18–25. doi:10.1159/000100521
45. Perz J, Ussher JM, Gilbert E (2013) Constructions of sex and intimacy after cancer: Q methodology study of people with cancer, their partners, and health professionals. *BMC Cancer* 13:270. doi:10.1186/1471-2407-13-270